Patients and care providers perception of the current heart failure health care system – A survey within Stockholm County

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Patienters och vårdgivares syn på den befintliga hjärtsviktsvården - En undersökning inom Stockholms Län

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Abstract

The prevalence of heart failure is increasing. This is affecting the health care system; thus, making it important with change to meet the new demands. Many effective ways of treating heart failure exists, but changes are required in order to implement them. Before changes can be made, it is important to find current problem areas within the existing heart failure health care system.

This study aimed to present an image of current problem areas within the heart failure health care system; in order to do so, it was necessary to speak with both care providers and heart failure patients. A total of 26 heart failure patients and 27 care providers working with heart failure patients in Stockholm County participated in the study. The participants answered survey questions concerning the heart failure care.

The results from the care providers were consistent; they thought the patients’ heart failure awareness and the patient education they had received were problems within the heart failure care. In addition, they thought it was necessary for the patients to be active in their care and meet with different professions within the health care. Heart failure patients showed to be a diverse group of individuals; they wanted different kind of care and showed differences in how active they wanted to be. The results also showed differences between the care providers and patients’ perception of the heart failure care.

The heart failure care needs to be more individualized to meet each heart failure patients’ needs. It is important with more patient education and to actively work with self-care. In addition, it is important that care providers get sufficient heart failure knowledge and to offer the patients the opportunity to meet with different care provider professions.

Key words: care provider, health care system, heart failure, individualized care, patient, patient education, Stockholm County
Sammanfattning


Resultaten från vårdgivarna var konsekventa, de ansåg att patienternas kännedom om hjärtsvikt och den hjärtsviktsutbildning de fått var problemområden. Vårdgivarna ansåg vidare att det var viktigt för patienterna att vara delaktiga i sin vård, samt att de skulle få träffa olika typer av vårdgivare. Hjärtsviktspatienterna visade sig vara en blandad grupp, de ville ha olika typ av vård samt vara olika mycket aktiva i egenvård. Resultaten visade också att det fanns skillnader mellan vårdgivarnas och patienternas uppfattning av hjärtsviktsvården.


Nyckel ord: hjärtsvikt, individanpassad vård, patient, patient utbildning, sjukvårdssystem, Stockholms Län, vårdgivare
Preface
This project is a bachelor thesis project carried out at the Royal Institute of Technology during the spring semester in 2014. The study was carried out on behalf of the Karolinska Innovation Centre and in corporation with Boston Scientific.

We would like to thank our supervisor Nina Lahti, from the Karolinska Innovation Centre, for her help with the project; and Helen Skogsberg for her help at the different wards at Karolinska University Hospital in Huddinge.

We would also like to thank Laura Cormican, from Boston Scientific, for all her help with the data analysis.

At last, we are grateful to the personnel at M88 who let us interview their heart failure patients.

Hanna Granholm
Linda Axwik
KTH STH
Maj 2014
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1 Introduction

Major parts of the human population are changing their lifestyles towards a more sedentary way of living; furthermore, the health care system is improving thus making people live longer. Old age, poor exercise and bad food habits can be contributing causes for heart failure. Heart failure is a severe and deadly disease, affecting both the diagnosed persons and their relatives. Seeing that heart failure is an increasing problem there is a need for change in the heart failure health care system.

A person with heart failure needs lifelong treatment, which leads to a continuous contact with the health care system. In order for them to receive the best possible care, a new health care system needs to be formed. This study aimed to present an image of current problem areas within the heart failure health care system so that the provided care can be improved. This work was an initial part of a bigger study, conducted with the Karolinska Innovation Centre and Boston Scientific.

1.1 Aims and objectives

The aim of this study was to present an image of current problem areas within the heart failure care. In order to do so, it was necessary to identify where further investigations were needed to improve the situation for heart failure patients.

In order to find problem areas there was a need to:

a) Clarify heart failure patients’ opinion towards different care solutions
b) Look into the communication pathways between care providers
c) Look into the communication between care providers and patients
d) Identify gaps between patients and care providers perception of the current heart failure care

1.2 Restrictions

The heart failure health care system is a wide research field. In order to present a result in a 10 weeks’ time it was necessary to restrain the project. It is a difficult task to know where improvements are needed; we chose to focus this work on finding prominent problem areas. In order to find them, it was necessary to establish patients and care providers perception of the current heart failure care.
2 Background
Heart failure is an increasing problem in major parts of the world, it is estimated that the prevalence of heart failure is 1-2% in the western society (Mosterd and Hoes, 2007). An aging population and more successful heart failure care, leading to a higher rate of survival after serious disease, are two factors which explain the increasing number of heart failure patients (Jaarsma et al., 2013, Hawkins et al., 2013). Numbers from RiksSvikt show that the one year mortality rate in Swedish hospitals was 15% in the year 2012 (RiksSvikt, 2012) and since heart failure is a deadly and complex disease it is of utmost importance to find the optimal heart failure health care system.

There are currently several treatment methods and guidelines regarding heart failure care but no effective way of implementing these in the heart failure health care system. The most effective model is yet to be discovered (Jaarsma et al., 2013).

2.1 Heart failure
When the heart no longer has the capacity to deliver enough oxygen to the cells it suffers from heart failure. At first the heart tries to compensate for this by enlarging the heart chambers, increasing the muscle mass or increasing the pulse. However, these actions cannot cure heart failure, only compensate for the lack of capacity during a period of time. (Heartline, 2012)

A person with heart failure often suffers from shortness of breath and fatigue, these symptoms are caused by the decreasing amount of oxygen delivered to the cells. Other symptoms are oedemas and weight gain, caused by the up built of fluid in the body. If heart failure goes untreated the mentioned symptoms will worsen and the affected person is more likely to die an early death. (Hjärt- & Lungfonden, 2014c)

There are several causes for heart failure. One of them is high blood pressure which increases the pressure on the heart, thus causing a higher workload. Another reason for heart failure is physiological defects on the heart which can cause a heart valve leakage. A heart valve leakage leads to a higher workload due to the inevitable increasing number of heart beats. Heart attack, infection, disease or birth defects can be reasons for the physiological defect on the heart. Other reasons for heart failure are severe lung disease and diabetes. (Läkemedelsverket, 2006, Hjärt- & Lungfonden, 2014b)

2.2 Treatments
As mentioned before, there are several types of treatments for heart failure. The goal of heart failure treatment is, according to the European Society of Cardiology, to “relieve symptoms, prevent hospital admission and improve survival” (McMurray et al., 2012). Since heart failure is caused by various reasons the treatment may depend on the cause. It is also common for a patient with heart failure to suffer from multiple diseases, which can complicate the treatment. (McMurray et al., 2012)

In order to relieve the workload of the heart and relieve the symptoms connected with heart failure, it is often important to make lifestyle changes. These changes may include no smoking, regular exercise, diet changes and control of the sodium and liquid intake. Furthermore, it is important to have a continuously control of the weight, since a rapid change in weight can cause acute symptoms. Even though a heart failure patient make lifestyle changes, it is necessary with continuous medical appointments in order to monitor the condition. (AmericanHeartAssociation, 2012)
2.2.1 Drugs
Drugs are an essential part in the treatment of heart failure. One example is the Angiotensin-converting enzyme (ACE) inhibitors; ACE inhibitors lessen the workload of the heart through a relaxation of the blood vessels, thus lowering the blood pressure. Beta blockers and diuretics are other drugs that lessen the workload of the heart. Beta blockers interfere with different stress responses, whereas diuretics decrease the amount of fluid in the body which also removes eventual oedemas. (Hjärt-&Lungfonden, 2014a)

2.2.2 Surgery
Heart failure can be treated with implantation of medical devices; the most common ones are implantable cardioverter-defibrillator (ICD) and cardiac resynchronization therapy (CRT). When a patient suffers from milder heart failure symptoms an ICD can be implanted. ICDs give the heart an electrical shock when the heart goes into dysrhythmia. It has been shown that ICDs reduces the mortality of heart failure patients who have suffered from cardiac arrest (McMurray et al., 2012). CRTs synchronize the contraction of the ventricles by giving both the right and left ventricle an impulse; this helps the heart to pump the blood more efficiently. (Hjärt-&Lungfonden, 2014a)

A last resort for a patient with severe heart failure is heart transplantation and it is the only cure for heart failure. Heart transplantation is an uncommon treatment for heart failure, both due to limitation of donor hearts and the severity of the patient’s health. The age limit for heart transplantations is currently 65 years, but exceptions can be made. (BritishHeartFoundation)

2.3 The heart failure health care system
At this moment there is no clear picture of the heart failure health care system. It is known that there is a difference between patients treated at the hospitals and in the primary care; for example, patients treated in the primary care are more often stable in their heart failure disease, elderly and suffers from multiple chronic diseases. Heart failure patients are only hospitalized if they are suffering from acute symptoms, this health care is the most costly compared with other heart failure care (Socialstyrelsen, 2008). Even though good heart failure care exists, many patients are today undertreated. For example, there is a possibility that heart failure patients receive too little medication. This is something that impacts the patients’ quality of life, mortality rates and readmissions. (LandstingetSörmland, 2012)

The Swedish guidelines for heart failure treatments were released 2008 by Socialstyrelsen. In 2012 the European Society of Cardiology released their guidelines for diagnosis and treatments for acute and chronic heart failure.

It has been shown that a nurse led heart failure clinic improves survival and self-care behaviour (Stromberg et al., 2003). In addition, it has been shown that heart failure patients who receive education about the symptoms and treatment for heart failure are healthier than non-educated patients. The educated patients used fewer medications and lived longer compared to the patient who did not receive an education about heart failure. (Juilliere et al., 2013)
3 Materials and Methods

The study was conducted through anonymous surveys. The aim was to identify current problem areas within the heart failure health care system to get an overall picture of the situation concerning the heart failure care today. In order to find these problem areas it was necessary to speak with both care providers and heart failure patients. A survey allowed a sufficient amount of data to be collected during a limited period of time.

3.1 Survey design

There were two different sets of surveys, one for the heart failure patients and one for the care providers. See Appendix A for the patient survey and Appendix B for the care provider survey. In order to find problem areas within the heart failure health care system the surveys were covering different themes. Focus was on communication between care providers and patients, communication pathways between care providers, patient needs, knowledge about heart failure and participation in self-care; these themes were chosen after initial literature studies. Gaps between patients and care providers perception of the heart failure care were identified by asking them the same types of questions. The character and subjects of the questions was determined after discussions with Gisela Jönsson, a post graduate at KTH who is familiar with surveys, and literature studies about heart failure.

The survey had a cross sectional design; it contained multiple indicator answers, namely a five point Likert scale and open ended questions in order to find unknown variables. This design made the survey both qualitative and quantitative. Since the surveys were given to people with different background, it was important to make sure that the questions were easy to understand. In order to control the questions in the survey, it was handed out for feedback to persons outside the project and revised before the conducted interviews.

3.2 Samples

Data from the care providers and the heart failure patients was gathered during a four week period. The different participants included: physicians, nurses, district nurses, a hospital bed coordinator and heart failure patients. All the interviews were conducted in Swedish; the attached surveys, Appendix A and B, have been translated from Swedish to English.

The participants were picked from different instances in the public and private care sectors from different parts of Stockholm County. The hospitals and health care units where the surveys took place were Karolinska University Hospital (KS), both Huddinge (KSH) and Solna (KSS), Dalens ASIH (avancerad sjukvård i hemmet), Storvretens vårdcentral, Hjärt och kärllcentrum Södertälje AB and Stockholm Heart Center. Hjärt och kärllcentrum Södertälje AB and Stockholm Heart Center are private outpatient cardiology clinics and Storvretens vårdcentral is a private primary care unit. The interviews at KS included participants from the wards: M81, M82, M83, M88, AKVA, AVA1, AVA2 and a hospital bed coordinator. M81, M82, M83, AKVA, AVA 1 and AVA2 are closed wards. See Table I for the number of participants from each health care unit.

After an explanation of the purpose with the survey the participants were asked if they wanted to participate. See Appendix C for the information about the project given to the participants.
Each interviewed patient had received a heart failure diagnosis from a physician. The participants chosen had a good cognitive ability and spoke Swedish in order for them to understand the questions. Patients from M88 were asked to participate when they came in for their booked appointments with their heart failure nurses. At the closed wards, a nurse asked the heart failure patients if they wanted to participate in the survey.

Table I Distribution of the participants

<table>
<thead>
<tr>
<th></th>
<th>Physician</th>
<th>Nurse</th>
<th>District nurse</th>
<th>Patient</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>KSH/KSS (excluding M88 and</td>
<td>0</td>
<td>14</td>
<td>0</td>
<td>16</td>
<td>30</td>
</tr>
<tr>
<td>hospital bed coordinator)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M88</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Hjärt och kärlcentrum Södertälje AB</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Stockholm Heart Center</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Dalens ASIH</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Storvretens vårdcentral</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Hospital bed coordinator</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>4</td>
<td>21</td>
<td>2</td>
<td>26</td>
<td>53</td>
</tr>
</tbody>
</table>

The care providers chosen to be interviewed at KS (excluding M88 and the hospital bed coordinator) were those who had time to participate during our time at their wards. This data was collected during two days, one day at KSH and the other on KSS. All the other care providers were interviewed at booked appointments. The hospital bed coordinator had no patient contact and could therefore not answer all the questions in the survey.

The survey was conducted orally with the patients, thus making it possible to explain the questions if necessary. Most of the care provider interviews were conducted orally; but since care providers have a limited amount of time, some of the surveys needed to be handed out in order to get a sufficient amount of data. If the participants’ answers were unclear they were asked to elaborate.

### 3.3 Data analysis

The participants’ answers were translated from Swedish to English and collected in an Excel file. The data was collected according to where the participants came from and if they were a care provider or a heart failure patient. The grades on the Likert scale were converted into numbers, see Table II. Eventual comments after were removed and a categorization of the data from the open ended questions was made before the analysis. In Appendix D the different categories are explained. The analysis of the data was compiled with QlikView.

Table II Likert scale

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Fully agree</td>
</tr>
<tr>
<td>4</td>
<td>Mostly agree</td>
</tr>
<tr>
<td>3</td>
<td>Party Agree</td>
</tr>
<tr>
<td>2</td>
<td>Agree a little</td>
</tr>
<tr>
<td>1</td>
<td>Don’t agree</td>
</tr>
</tbody>
</table>
4 Results

Below is the presentation of the survey results. The charts used in the results are either showed in this chapter or in Appendix E.

4.1 Patient participation

A great majority, 93%, of the care providers fully agreed that it is important for the patients to be active in their heart failure treatment and self-care. The patients’ answers were more scattered, 42% fully agreed that it is important for them to be active in their care and 31% do not think it is important. See figure 1 for their answers.

Almost all of the patients thought it were important to have regular contact with physicians and nurses, 88.5% fully agreed that it was important to have regular contact with a physician and 73% fully agreed that it is important to have regular contact with a nurse. In total, the care providers thought it were more important for the patients to have regular contact with a nurse than with a physician. In addition, all of the care providers were positive or neutral to the statement that it is important for the patients to have regular contact with a physician or a nurse. Compared with the patients, the care providers were more positive towards the opportunity for patients to decide when they can meet with care providers.

When it came to the opportunity to be offered regular contact with physiotherapists, dieticians and counsellors the patients’ answers were not as positive as the care providers’ answers; a majority of the care providers wanted patients to be offered this. Around half of the patients fully agreed that they would like to be offered the opportunity to meet a dietician and a physiotherapist but only 30.8% fully agreed that they want to be offered the opportunity to meet a counsellor.

Younger patients, from age 50 to 80, were more prone to agree that they want to be active in their heart failure care, see figure 2. All of the participants between 50 and 60 fully agreed that they wanted to be active in their own care, whereas none of the participants over 90 wanted to be active in their own care. The heart failure school is a school for heart failure patients and their
relatives. In the heart failure school they get to meet with different care professions and they teach the patients about heart failure and how to be active in their care. None of the patients over 80 had heard of this school. On the other hand it was not possible to see if the patients that had participated in the heart failure school were more prone in wanting to be active and receive information about their care, compared to those who had not participated.

Half of the heart failure patients thought that a care plan created together with their care providers would be a good idea. Furthermore, most of the care providers, 77.8%, thought that it would be good for the patients care if they were able to create individualized care plans together with their patients. When asked which tools they would need to create these care plans the most frequent answer was more time. It was also common that the care providers thought they needed more knowledge about heart failure and how to work with individualized care plans. Guidelines, templates and more resources are also examples of what some of the care providers would need in order to be able to create individualized care plans for their patients.

The patients were overall negative towards the idea to meet other heart failure patients, a total of 65.4% did not agree at all, while 51.9% of the care providers thought that it was important for heart failure patients to meet other heart failure patients. The patients were more positive towards the idea of meeting other heart failure patients to engage in self-care in a group.

4.2 Communication

A majority of the patients, 61.5%, fully agreed that they understand what the care providers tell them about their health, see figure 3a). In contrast to this, only 18.5% of the care providers fully agreed that the patients understand what they tell them about their heart failure, see figure 3b). More specifically, the care providers answers depended on where they work, the care providers from KS did not agree as much as those from smaller clinics.

When asked what reasons they think caused the patients not to understand, many pointed out the patients’ poor cognitive abilities and their lack of understanding for the severity of their heart failure. For example one care provider said “*Mostly the patients understand what you tell them, but you have to be consistent in frequently telling the patients what they can and cannot do. You have to get the patient to understand the relation between following restrictions and their health.*” These answers also depended on where they worked, see figure 4.
As many as 88.5% of the patients felt that they can tell the care providers everything regarding their health, the same number felt that the care providers listen to them when they talk about their health.

When it came to distance communication the answers from the patients and care providers did not correspond. Half of the patients would not feel comfortable to communicate on distance with their care providers while 30.8% would feel comfortable to do so, the patients answers did not distinctly depend on their age, see figure 5. The care providers’ answers were more diverse, a majority of them were positive towards distance communication but 14.8% did not agree at all.

On the question “I would like to be offered the opportunity of heart failure care at home” half of the patients fully agreed and the other half did not agree at all. A patient commented that it was not needed as long as he could come to the hospital himself. The different answers were spread among the ages but it was possible to see that patients over 80 were more positive towards the idea of home health care. 77.8% of the care providers thought that the patients would like to be offered this.

4.3 Information
The patients and care providers had similar opinions regarding how they wanted to receive, respectively give information about heart failure. A majority of the patients and care providers preferred oral information. The difference between the two groups was that almost half, 40.5 %, of the care providers want to give written information, whereas only 14.3% of the patients want to receive written information about heart failure. Many of the care providers pointed out that it is important to give the patients both oral and written information; for example one care provider said “First oral and then brochures. It is important that they can go home and read in peace and quiet”.

All care providers who answered questions about if they thought it was important for patients to receive information about the disease and treatment for heart failure were positive towards this statement. Similarly, 76.9% of the patient thought it was important to receive information about the
disease heart failure and 88.5% of the patients fully agreed about the importance of receiving information about the treatment for heart failure. When the care providers answered the question “When, in the heart failure care pathway, do you prefer to give the patients information about heart failure?” a majority said that the patients should receive the information when they were diagnosed and then continuously after that. On the question “Which health care unit do you think should deliver this information?” the answers differed, see figure 6.

On the question concerning which care provider gives the patient information about heart failure the majority of the participants answered that the physicians gave the patients that information. 14.3% of the patients answered that it were heart failure nurses that gave them information about heart failure; however, only 4.7% of the care providers answered the same. 7.1% of the patients answered that they had not received any information about heart failure, see figure 7.

**4.4 Hospital organization**

Among the care providers 63% knew that a heart failure school exists. Of these care providers only 53% knew what the heart failure school does. In the patient group 23.1% had heard of the heart failure school.

A majority of the care providers, 44.4%, did not meet staff from other care provider units in order to exchange experiences about heart failure; this answer did not depend on where they worked. When asked if they wanted to visit other care providers the majority were positive to the statement. The only two negative answers came from a small cardiology clinic, see figure 8.
The care providers did not think that patient information transfer between different care units was a problem, only 3.7% fully agreed to it being a problem. However, if they lacked information about the patient 72.2% stated it was because of different journal systems. 88.5% of the interviewed care providers use Take care as their journal system.

Patient education and patient care were the largest categories on what the care providers thought were good with the current heart failure care. A care provider answered “That there is a lot of focus on informing the patient. Good brochures to read.” Another participant answered “The outpatient heart failure clinic and the heart failure school.”

4.5 Challenges

When the care providers were asked what the greatest challenge in heart failure care is, it was possible to see differences in their answers depending on where they worked, see figure 9. KSH were the only care provider that mentioned patient motivation as a challenge, while three smaller clinics mentioned time. The patients’ heart failure awareness and compliance were present at all workplaces. A nurse from KSH commented “To get the patient to understand the gravity of the disease and to get them more active in the treatment”, on what the greatest challenge was.

The care providers had different opinions on which patients’ needs were not met from the health care system today. Two separate answers were “Spreading information about heart failure and its treatments, especially for the nurses. To let the nurses continue some of the care for the patients after they leave the hospital, not only the physicians.” and “Important that the patient learn how to adjust the medication. It is important with self-care and education to the patients and the health care providers.” More education about heart failure was the single largest item in the chart, but patient education, information about self-care and better structure were the second largest.
5 Discussion
The care providers gave a uniform picture of current problem areas within the heart failure care, the greatest challenges according to them were the patients’ heart failure awareness and patient compliance. They would also like the patients to be more active in their treatment, so called self-care, something that has shown to decrease the number of shown heart failure symptoms (Shao et al., 2013). Heart failure patients consist of a diverse group of individuals, thus making it hard to find a consistent patient view on the heart failure care.

5.1 Patient participation
Heart failure is a chronic disease and it is therefore necessary for the patients to take an active role in their treatment in order to improve the outcome. It was clear that patient participation in the treatment and self-care were something the care providers thought were important. This can be explained by the care providers’ knowledge about heart failure. Patients on the other hand, were not as prone to agree that this was something they thought were necessary. Either this may depend on the patients’ lack of knowledge about the benefits with self-care or their satisfaction with the current provided care. One reason, identified by Riegel and Carlson, for patients doing nothing about significant heart failure symptoms, is the patients lack of believe in that self-care can relieve these symptoms (2002).

The fact that a majority of the patients want to have regular contact with physicians and nurses, shows that they want to be part of their care. In addition to this the patients wanted to receive information about heart failure, its treatments and to create a care plan together with their care providers. These things are all done together with the care providers and do not demand major efforts from the patients.

When asked about physiotherapist, dietician and counsellor their answers were not as positive and these meetings would demand more effort from the patients. Meetings with these care professions could be a help for the patients to make lifestyle changes, which is necessary in order to maintain a good health. Since the care providers were positive towards the idea for patients to meet with different kind of care professions this is something that could be implemented in the existing health care system.

The patients were not positive towards the idea of meeting other heart failure patients to speak about their experiences; however, they were more positive towards the idea of engaging in self-care with other patients which might be a way of making them more active in their own care.

5.2 Age differences
Younger patients were more prone in wanting to be active in their care, which can be explained by their mental and physical ability to participate. Moreover, it was possible to see that patients over 80 were more positive towards the idea of home health care, something that could be connected to their physical abilities. The care providers should bear these things in mind when they offer different care solutions for the patients. Since no patient over 80 had heard of the heart failure school the care providers might already think about giving individualized information.

Since it was not possible to clearly see if age mattered when it came to distance communication it is important to carefully listen to what the patients want. Seeing that only 30% of the patients agreed
that they would feel comfortable to communicate on distance with their care providers, this might need more thought before it is implemented in the existing heart failure health care system.

5.3 Patient education
Information about heart failure is today given in multiple ways, something that both care providers and patients appreciate. Many care providers also thought that the patient education was a good part of the existing heart failure care, showing the importance of this area. The care providers pointed out that it is important to give patients information continuously, multiple times and in different ways and this form of education have been proven to work (Fredericks et al., 2010).

Most of the information comes from physicians and nurses, this is probably due to the more frequent meetings between these care providers and the patients. Since there was a wish among the care providers to involve physiotherapists, dieticians and counsellors in the heart failure treatment, it is important that they as well take active part in patient information and education.

The care providers thought that more patient education was needed in order to meet the patients’ needs. Paul (2008) writes that with the right hospital discharge patient education hospital readmissions decrease.

One problem concerns the fact that patients who had participated in the heart failure school showed no more willingness to be active in their care compared with those who had not participated. This shows that the will to participate depends more on the patients’ personality than their knowledge about heart failure. Still, it is important that every heart failure patient receives education about heart failure in order to support those wanting to have an active role in their care. Since other studies have shown that patients educated about heart failure are healthier than non-educated patients, heart failure education is an important tool in the heart failure care (Juilliere et al., 2013).

5.4 Patient and care provider communication
A major problem which was discovered concerns the communication between patients and care providers. In contrast to the care providers, the patients feel that they understand what the care providers tell them. Only around a fifth of the care providers think that the patients understand what they are told. The reasons for the patients lack of understanding, according to the care providers, is mainly due to bad cognition and poor heart failure awareness. Since no further investigations was made on this subject it is not possible to say which group is right; however, heart failure causes fatigue which matches the care providers view.

Seeing that the two groups have such different views on the subject it is important to clarify why this is the reason and how it can be avoided. In order for the patients to take an active role in their treatment it is important that they understand the information they are given.

5.5 Care providers
The care providers within the heart failure care system were positive towards the idea of meeting other care providers. Such meetings could improve the knowledge about different ways of treating heart failure, something which is important since the care needs to be diverse in order to meet each individual patient’s need. Seeing that not all of the care providers knew about the heart failure school, communication improvements are needed. If more care provider professions are to take an
active part in the heart failure treatment, it is important that all care providers know what treatments are available for the patients.

If the care providers are to educate the patients, and provide them with the best possible care, it is important that they learn more about heart failure. This is also something that they thought was necessary in order for them to meet the patients’ needs.

5.6 Information flow
An imminent majority of the participating care providers uses Take care as their journal system, which facilitates transferal of patient information between different care providers. Since transferal of patient information was not thought to be a problem, it seems that the Take care journal system is working well.

Since both care providers and patients were positive towards the idea of an individualized care plan it could be good to create a template for this in the Take care journal system. This could save time for the care providers and help them to take note of important key indicators for their heart failure patients. Such an individualized care plan could help the care providers to give adapted information to each patient and allow the patients to get support concerning their part in the treatment. These individualized care plans is a step towards a more individualized care which is needed in order for each patient to get the best possible care.

5.7 Limitations
The participating patients came from different backgrounds and had received different care, this is something that might have affected their perception of the questions. Interviewed care providers worked in a stressful environment; thus, giving them a limited amount of time to participate in the survey and might have caused them to hasten through the questions.

The majority of the samples were from the hospital environment; this may have given an angled view of discovered problems. The results might have been of another character if persons diagnosed with heart failure but not currently visiting health care units were interviewed. In addition, a more even distribution among the care provider professions might have given different results.

Some of the questions in the survey were open ended, which enriched the answers in the survey, but made it harder to analyse.

5.8 Further investigations
The aim of this study was to find current problem areas within the heart failure health care system, this would allow future studies to continue investigating discovered problems. The most prominent problem areas found concerns the communication between care providers and patients, patient participation in their care and education about heart failure.

Further studies should therefore focus on how:

a) care provider and patient communication can be improved
b) patient education can help heart failure patients with self-care
c) different care provider professions can improve patient participation in self-care
d) heart failure knowledge can be spread among care providers and heart failure patients
6 Conclusion
The goal with this study was to identify initial problem areas in order to know where further studies were needed. The results from this study indicate that the heart failure care needs to be more individualised in order to meet each heart failure patient’s need; seeing that heart failure patients have diverse opinions regarding how they want to receive their care. The care providers shared opinions regarding how the heart failure care should be performed; they wanted more self-care and would like the patients to meet with different professions within the heart failure care. In addition, they want more heart failure knowledge and patient education. Since the care providers felt that heart failure patients not always understand what they tell them, it is important with further investigations on how the communication between care providers and patients can be improved. This is an initial study with a small participant base, it is important to bear in mind that further investigations are needed before changes can be made.
7 Bibliography

AMERICANHEARTASSOCIATION. 2012. *Lifestyle Changes for Heart Failure* [Online].


LÄKEMEDELSVERKET. 2006. *Diagnostik och behandling av kronisk hjärtsvikt* [Online].

Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *Eur J Heart Fail*, 14, 803-69.


Patient survey

Appendix A

Mark the option that fits your views best

**Background**

1. Gender:  
   - Female  
   - Male
2. Age:  
   - Under 50  
   - 50-60  
   - 61-70  
   - 71-80  
   - 81-90  
   - over 90
3. What year did you receive your heart failure diagnosis: _____
4. Where did you receive your heart failure diagnosis? (e.g. primary care unit, hospital)
5. Do you have a pacemaker?  
   - Yes  
   - No
6. If you have a pacemaker, why did you receive it?
7. What does your treatment consist of? (e.g. medication, pacemaker, change in diet)
8. Are you in contact with, and receive help from, ASIH?  
   - Yes  
   - No
9. Do you have home care, if you do what does it consist of?

**Communication between patient and care providers**

10. The care provider listen to what I have to say about my health

   - Fully agree  
   - Mostly agree  
   - Partly agree  
   - Agree a little  
   - Don’t agree

11. I feel that I can talk about everything regarding my health with my care providers

   - Fully agree  
   - Mostly agree  
   - Partly agree  
   - Agree a little  
   - Don’t agree
12. I know who to contact when there is a change in my health

*Fully agree*  *Mostly agree*  *Partly agree*  *Agree a little*  *Don’t agree*

13. If you do not know who to contact when there is a change in your health, what do you lack in order to do so?

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

14. I understand what the care providers tells me about my health

*Fully agree*  *Mostly agree*  *Partly agree*  *Agree a little*  *Don’t agree*

15. If you do not understand what they tell you, what do you think that depend on?

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

16. Today, I receive most of my information about heart failure

*From a physician*  *From a nurse*  *From next of kin*  *On my own initiative*  *Other:_____

17. In what way would you prefer to receive information about heart failure?

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

18. I know who to contact when I want to learn something new about heart failure

*Fully agree*  *Mostly agree*  *Partly agree*  *Agree a little*  *Don’t agree*

19. How could the contact between you and the health care system be improved?

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________
APPENDIX A

20. I would feel comfortable to communicate with my care provider by remote (telemedicine)

Fully agree       Mostly agree       Partly agree       Agree a little       Don’t agree

Your needs

21. I would prefer to have contact with the health care system (MULTIPLE CHOICES)

By home visits, By health care centres, By hospitals, By telephone, By letter, By Internet, Other: _____

22. It is important for me to receive information about the treatment of heart failure

Fully agree       Mostly agree       Partly agree       Agree a little       Don’t agree

23. It is important for me to receive information about the disease heart failure

Fully agree       Mostly agree       Partly agree       Agree a little       Don’t agree

24. Is there something about heart failure, or the heart failure treatment, that you would like to receive more information about?

25. It is important for me to understand every step of my heart failure treatment

Fully agree       Mostly agree       Partly agree       Agree a little       Don’t agree

26. I would like to meet other heart failure patients in order to exchange experiences

Fully agree       Mostly agree       Partly agree       Agree a little       Don’t agree

27. It is important for me to have regular contact with a physician

Fully agree       Mostly agree       Partly agree       Agree a little       Don’t agree

28. It is important for me to have regular contact with a nurse

Fully agree       Mostly agree       Partly agree       Agree a little       Don’t agree
29. I would like to be offered the opportunity of regular contact with a dietician

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

30. I would like to be offered the opportunity of regular contact with a physiotherapist

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

31. I would like to be offered the opportunity of regular contact with a counsellor

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

32. I would like to be offered the opportunity of heart failure care at home

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

33. I would like to be offered the opportunity to decide when I can meet my care providers

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

34. In what way could you benefit from planning your meetings with the care providers?

__________________________________________________________________________________

__________________________________________________________________________________

35. It would be good to create a goal for my heart failure treatment

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

36. It would be good if I could create a care plan of my heart failure care together with my care providers

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

37. It would be good if all the care providers worked according to my care plan

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

38. What needs, regarding your heart failure care, is not met from the health care system today?
39. What do you find good about the hearth failure care?

40. Do you have any positive encounters with other care providers that you think the heart failure care could learn from?

Participation in the care, Self-care

41. I want to be active in my heart failure treatment

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

42. I know what I can do to improve my health

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

43. I would like to receive more information about how I be a part of my heart failure treatment

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

44. I need more support to start my self-care

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

45. If your need support, what type of support could that be?

46. I would like to be offered the opportunity to perform self-care together with other heart failure patients

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>
APPENDIX A

47. Have you ever heard of the heart failure school?
Yes, I have participated  Yes, I know what it is but I have never been there
Yes, I have heard the name but do not know what it is  No, I have never heard of it

Other

48. Do you have any overall thought on how the heart failure care could be improved?


49. Do you have any information you would like to share with a newly diagnosed heart failure patient?


50. What would make you feel more confident in your heart failure care?


51. Is there anything else you would like to add?


52. Was there anything about the survey you did not understand?


Care provider survey

Mark the option that fits your views best

Background

1. For how long have you been active within the health care sector?_______
2. For how long have you been active within the heart failure care?___________
3. Job title and work area

4. Workplace (ASIH, primary care unit, hospital etc.)

5. How often do you treat heart failure patients? __________

6. How do you treat heart failure patients? (e.g. Medication)

7. When do you remit patients to other care providers?

8. Do you know what the NYHA definitions are? Yes No

Communication between patient and care providers

9. I document what the patients tell me about their health
   In an electronic medical journal    In a medical paper journal    Other:___

10. Are you working with templates specified for patients with heart failure in your work with documentation?
11. I feel that I can take note of sufficient amount of information about the patients’ health in order to perform my work in the best way possible

Fully agree   Mostly agree   Partly agree   Agree a little   Don’t agree

12. I feel that the patients understand what I tell them about their heart failure

Fully agree   Mostly agree   Partly agree   Agree a little   Don’t agree

13. If you feel that there is something that the patients do not understand, what could that be?

___________________________________________________________________________

___________________________________________________________________________

14. I feel that I can give sufficient amount of information about heart failure to my patients

Fully agree   Mostly agree   Partly agree   Agree a little   Don’t agree

15. Today, the patients mostly receives their information about heart failure from

A physician   A nurse   Next of kin   Own initiative   Other: ___

16. In what way do you prefer to give information to the patients?

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

17. When, in the heart failure care pathway, do you prefer to give the patients information about heart failure?

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

18. Which health care unit do you think should deliver this information?

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________
19. I would feel comfortable to communicate with my patients by remote (telemedicine)

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

20. I would feel comfortable with remote monitoring of the patients

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

21. I would prefer to analyse the gathered data by myself

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

**Communication between different care providers**

22. Do you believe that you follow the latest guidelines regarding heart failure care?

- Yes
- No

23. Do you believe other care providers are following the latest guidelines regarding heart failure care?

- Yes
- No

24. How do you take note of the latest guidelines regarding treatment of heart failure from other care units today?

- Telephone
- Mail
- Newsletter
- Information meetings
- Study visits
- Personal meetings
- Other: ___

25. I find the current communication system between different care units regarding information about heart failure treatment to be good

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

26. I meet staff from other care units in order to exchange experiences about the heart failure care

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

27. What works well in the communication between care units?
28. What does not work well in the communication between different care units?

29. Sometimes, I do not have sufficient amount of information about the patients earlier treatments in order to give optimal care

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

30. If you feel like you do not have sufficient amount of information about the patients, what kind of information do you lack?

31. I think that the transmission of patient information between different care units is a problem

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

32. If you lack information about the patient, what is the reason for that?

33. I know how the heart failure care is performed at other health care units

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

34. I would like to visit other health care units to see how they work with heart failure patients

| Fully agree | Mostly agree | Partly agree | Agree a little | Don’t agree |

35. Where do you turn when you do not know how to continue the treatment for a heart failure patient?
36. In what way would you like to acquire new information regarding heart failure care?

Patient need

37. It is important for patients to receive information about the treatment of heart failure

Fully agree    Mostly agree    Partly agree    Agree a little    Don’t agree

38. It is important for the patients to receive information about the disease heart failure

Fully agree    Mostly agree    Partly agree    Agree a little    Don’t agree

39. It is important for the patients to receive information about who to contact in the health care system regarding their heart failure

Fully agree    Mostly agree    Partly agree    Agree a little    Don’t agree

40. I think that the patients would prefer to have contact with the health care system by
(multiple choices)

Home visits    Primary care units    Hospitals    Telephone

Letter    Internet    Other:_____  

41. It is important for the patients to be active in their heart failure treatment

Fully agree    Mostly agree    Partly agree    Agree a little    Don’t agree

42. It is important for the patient to meet with other heart failure patients to exchange experiences

Fully agree    Mostly agree    Partly agree    Agree a little    Don’t agree

43. I think it is important for the patients to have regular contact with a physician

Fully agree    Mostly agree    Partly agree    Agree a little    Don’t agree
44. I think it is important for the patients to have regular contact with a nurse

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

45. It is important for the patients to be offered the opportunity to decide when they can meet care providers

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

46. It is important for the patients to be offered the opportunity of home care

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

47. It is important for the patients to be offered the opportunity of regular contact with a counsellor

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

48. It is important for the patients to be offered the opportunity of regular contact with a dietician

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

49. It is important for the patients to be offered the opportunity of regular contact with a physiotherapist

<table>
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<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

50. I would be good if the patients were active in self-care

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

51. It would be good if I, together with my patients, could create an individual care plan according to their current health status

<table>
<thead>
<tr>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Partly agree</th>
<th>Agree a little</th>
<th>Don’t agree</th>
</tr>
</thead>
</table>

52. What kind of tools would you need to be able to create individual care plan?
APPENDIX B

53. What do you find good about the current heart failure care?

54. What do you think needs to change in order to better meet heart failure patients’ needs?

55. What do you think is the greatest challenge in order to treat the heart failure patients?

56. Do you know that there exists a heart failure school?
   Yes  No

57. If yes, do you know what they do?
   Yes  No

Other

58. If you could make one change within the heart failure care, what would that be?

59. What information would you like to share with a newly diagnosed heart failure patient?
APPENDIX B

60. Is there something else you would like to add?


61. Was there something about the survey you did not understand?


Information to the participants

We are two students from KTH that are currently working with our bachelor thesis project; the aim with this project is to investigate the current heart failure care. We will investigate the heart failure care by identifying obstacles and needs from a patient- and care provider perspective. The surveys are handed out to patients and care providers in different care units within the Stockholm County. We have created one survey for the patients and one for the care providers. This is a first study to map the heart failure care in order to find where further investigations are needed.

We want you to answer on the questions based on your experiences of the heart failure care. Your answers are anonymous and will be used in order to map the heart failure care. Do not hesitate to ask if you have any thoughts about the survey.
Categorization of answers

For the analysis a categorization of the answers from the open ended questions was made. Below is a description of the categories.

**Patient survey**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>HF awareness</td>
<td>When the heart failure (HF) patient does not understand, or does not want to understand that they are sick. Often the diagnosis comes as a shock to the patient which makes it hard for them to accept the disease.</td>
</tr>
<tr>
<td>Patient education</td>
<td>What the patient is informed about regarding their HF: treatment, symptoms, further contact with the health care etc. and how the patient is informed.</td>
</tr>
</tbody>
</table>

**Care provider survey**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information for the patient</td>
<td>Information regarding their HF, treatment, symptoms, further contact with the health care etc.</td>
</tr>
<tr>
<td>Medical samples</td>
<td>Monitoring, e.g. blood pressure, heart rate, liquid intake, etc.</td>
</tr>
<tr>
<td>Medication</td>
<td>All kind of medication the patient gets, both pills and injections.</td>
</tr>
<tr>
<td>Patient care</td>
<td>Ordinary care for the patient, e.g. dressing wounds, bandage of swollen legs etc.</td>
</tr>
<tr>
<td>HF awareness</td>
<td>When the HF patient does not understand or does not want to understand that they are sick. Often the diagnosis comes as a shock to the patient which makes it hard for them to accept the disease.</td>
</tr>
<tr>
<td>Memory problems</td>
<td>Memory problems for the patient.</td>
</tr>
<tr>
<td>Language problems</td>
<td>If the patient does not understand the language due to various reasons.</td>
</tr>
<tr>
<td>Cognitive problems</td>
<td>Problems with the cognitive ability, which can lead to that the patient does not fully understand the symptoms, or treatment of the HF disease.</td>
</tr>
<tr>
<td>Lack of time</td>
<td>Lack of time for the care providers to meet with more patients, have longer meetings with the patients, to do more administration work for creating care plans for the patients e.g.</td>
</tr>
<tr>
<td>Time</td>
<td>See above.</td>
</tr>
</tbody>
</table>
**Care providers ignorance**  
For example, a care provider can skip informing the patient about HF before discharging the patient, just because they rely on someone else to take care of it.

**Own initiative**  
Both for the patient and care providers to be active in finding the information themselves.

**Networking**  
When the care providers use their contacts and people in their network to get information about new treatment methods etc.

**Lack of information**  
When a care provider lacks of information about what another care provider does e.g. how the patient can get in touch with them etc. Also when care providers lack of information about patients health status and their earlier treatments.

**Lack of remittance**  
Remittances can be forgotten or get stuck in the secretaries’ office.

**Hospital cultures**  
Many in the hospitals think they can do everything themselves. This can lead to that the patient will not get the best care possible due to poor judgment with the care providers.

**Journal records from other care providers**  
When information is missing about a patient, the most common reason for that is different journal systems between the different care providers.

**Outpatient HF clinic**  
M88, the nurse led outpatient HF clinic in KSH.

**HF school**  
An opportunity for HF patients, with relatives, to get information and education about the disease and treatment for HF.

**Acute care**  
The care a patient receives when they are in an acute condition.

**Diverse treatments**  
That there are a wide number of treatments available for patients with heart failure.

**Better accessibility**  
Some care providers want better accessibility to information about new treatment methods, guidelines and help from other care providers in their work.

**Better structure**  
In order to improve the HF care some care providers stated that a change in the hospitals organization structure is needed, e.g. a more clear care chain for the HF patients.

**Education about HF**  
More education about HF, both for care providers and for patients.

**Patient compliance**  
There is a difference between what is expected from the patient and what they actually do. Patient compliance concerns how the patients are following the care providers’ instruction.
Results

Appendix E

Figure 1 Care provider question 41. It is important for the patients to be active in their heart failure treatment

Figure 2 Care provider question 43. I think it is important for the patients to have regular contact with a physician

Figure 3 Patient question 27. It is important for me to have regular contact with a physician

Figure 4 Care provider question 44. I think it is important for the patients to have regular contact with a nurse

Figure 5 Patient question 28. It is important for me to have regular contact with a nurse
Figure 6 Care provider question 48. It is important for the patients to be offered the opportunity of regular contact with a dietician

Figure 7 Patient question 29. I would like to be offered the opportunity of regular contact with a dietician

Figure 8 Care provider question 47. It is important for the patients to be offered the opportunity of regular contact with a counsellor

Figure 9 Care provider question 49. It is important for the patients to be offered the opportunity of regular contact with a physiotherapist

Figure 10 Patient question 30. I would like to be offered the opportunity of regular contact with a physiotherapist

Figure 11 Patient question 31. I would like to be offered the opportunity of regular contact with a counsellor
Figure 12 Care provider question 45: It is important for patients to be offered the opportunity to decide when they meet care providers.

Figure 13 Patient question 33: I would like to be offered the opportunity to decide when I can meet my care providers.

Figure 14 Patient question 41: I want to be active in my heart failure treatment.

Figure 15 Patient question 47: Have you ever heard of the heart failure school?

Figure 16 Patient question 41: I want to be active in my heart failure treatment.
Figure 17 Care provider question 51. It would be good if I, together with my patients, could create an individual care plan according to their current health status.

Figure 18 Patient question 36. It would be good if I could create a care plan of my heart failure care together with my care providers.

Figure 19 Patient question 46. I would like to be offered the opportunity to preform self-care together with other heart failure patients.

Figure 20 Care provider question 42. It is important for the patient to meet with other heart failure patients to exchange experiences.

Figure 21 Patient question 26. I would like to meet other heart failure patients in order to exchange experiences.

Figure 22 Care provider question 12. I feel that the patients understand what I tell them about their heart failure.
Figure 23 Patient question 10. The care providers listen to what I have to say about my health

Figure 24 Patient question 11. I feel like I can talk about everything regarding my health with my care providers

Figure 25 Patient question 32. I would like to be offered the opportunity of heart failure care at home

Figure 26 Care provider question 19. I would feel comfortable to communicate with my patients by remote (telemedicine)

Figure 27 Patient question 20. I would feel comfortable to communicate with my care provider by remote (telemedicine)

Figure 28 Care provider question 46. It is important for the patients to be offered the opportunity of home care
Figure 29 Patient question 32. I would like to be offered the opportunity of heart failure care at home

Figure 30 Care provider question 16. In what way do you prefer to give information to the patients?

Figure 31 Patient question 17. In what way would you prefer to receive information about heart failure?

Figure 32 Care provider question 37. It is important for patients to receive information about the treatment of heart failure

Figure 33 Patient question 22. It is important for me to receive information about the treatment of heart failure
Figure 34 Care provider question 38. It is important for the patients to receive information about the disease heart failure.

Figure 35 Patient question 23. It is important to me to receive information about the disease heart failure.

Figure 36 Care provider question 56. Do you know that there exists a heart failure school?

Figure 37 Patient question 47. Have you ever heard of heart failure school?
Care provider question 26. I meet staff from other care units in order to exchange experiences about the heart failure care.

Care provider question 26. I meet staff from other care units in order to exchange experiences about the heart failure care.

Care provider question 34. I would like to visit other health care units to see how they work with heart failure patients.

Care provider question 31. I think that the transmission of patient information between different care units is a problem.

Care provider question 32. If you lack information about the patient, what is the reason for that?
Figure 43 Care provider question 53. What do you find good about the current heart failure care?

Figure 44 Care provider question 53. What do you find good about the current heart failure care?

Figure 45 Care provider question 54. What do you think needs to change in order to better meet heart failure patients’ needs?

Figure 46 Care provider question 54. What do you think needs to change in order to better meet heart failure patients’ needs?